

Public Advisory and Accountability Group

Summary Information

August 2024





1.1 What is the North West Secure Data Environment trying to achieve?

Vision

Make a positive health and care impact with people in the NW through better use of their data

Mission

To develop a SDE that offers a well-designed joined-up service, to the benefit all in the North West, that is efficient, secure and impactful

Purpose

- Reduce barriers to access for health data
- Reduce health and care inequalities
- Improve health & care services
- Develop public trust and acceptance of data use by managing data in a safe, legal and ethical way
- Develop a self-sufficient data ecosystem
- Improve research capabilities in the NW region

Values

- **Diverse:** We work with a wide range of people with different expertise and perspectives in the NW to achieve common goals
- **Open:** We ensure open discussion to help improve understanding
- **Accountable:** We believe in taking ownership and responsibility for our actions and their effects
- **Inclusive:** We engage with the public and stakeholders to ensure decision-making is transparent and people feel included



What does the PAAG do?

The PAAG is a group of people from the North West of England who help make sure that the North West Secure Data Environment (SDE) uses health data in a way that benefits everyone. This group gives advice and makes sure the project is doing the right things.

What does the group do?

- **Give Advice:** The group helps decide what is important for the project to focus on.
- **Share Ideas:** The group helps create materials like posters and information for the public.
- **Check Language:** The group makes sure that information is easy to understand.
- **Ask Questions:** The group makes sure that the project is using people's data safely and correctly.

Who is in the group?

- 18 residents: 6 from each area of the North West (Cheshire and Merseyside, Greater Manchester, Lancashire, and South Cumbria).
- **Non-voting members:** People who represent other organisations, like Health Watch.

How does the group work?

- **Meetings:** The group meets online every month for 2 hours. Sometimes they might meet in person.
- **Leadership:** The group has a Chair (leader) and a Deputy Chair. They help run the meetings.
- **Reporting:** The group reports to the Programme Board, which is responsible for making big decisions.

Respect and Behaviour

- Everyone in the group must be respectful.
- It's okay to disagree, but the focus should be on ideas, not people.
- Discussions should be helpful and make the project better.

What if there are conflicts of interest?

- Group members must tell the group if they have any conflicts of interest. This means if they have any other job or role that might affect their decisions in the group.

Payment

- Members get £50 for each meeting they attend. There will be a meeting register.
- One of the team will help arrange regular cheques or bank transfers.

How long can someone be in the group?

- Members serve for 1 year, and this can be extended to 2 years if needed.
- There may be other opportunities also too. Allowing ongoing involvement after time served on the PAAG.

Training

- New members will receive training to understand the project better. This will only take a few hours. No prior experience needed.

Diversity

- The group aims to include people from different backgrounds and communities to make sure everyone's voice is heard.



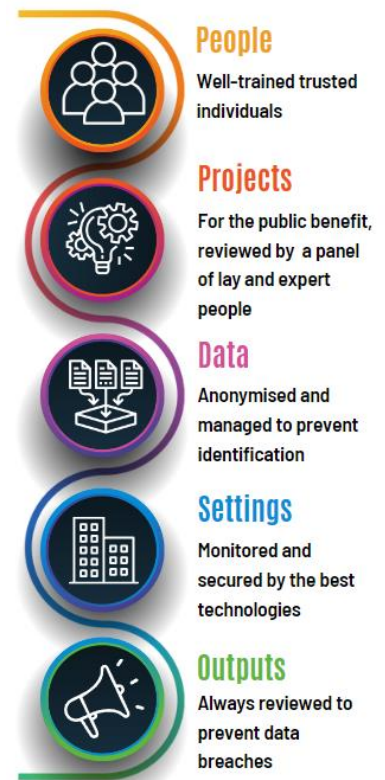
What will I do?

You will attend meetings that will last up to 2 hours. Here you will discuss a lot of things related to research, data and health. We will theme meetings to focus on the “Five Safes”. This is a set of ideas that helps us create data security. Together they form protective layers around the data to ensure confidentiality. Each session we will focus on one of the Five Safes which are

- Safe people
- Safe projects
- Safe data
- Safe setting
- and safe outputs which is what leaves the secure data environment to make a difference in the world!

This is the basic plan for our meetings. If any changes need to be made, we can do by agreement of the group. We expect it to change as we work and learn together.

- 1. Greetings and Apologies:** We start by welcoming everyone and introducing any new members. (5 minutes)
- 2. Review of Last Meeting:** We go over what was discussed in the last meeting and check that everyone has been paid. (10 minutes)
- 3. Updates and Recommendations:** This is the longest part of the meeting where we discuss updates and give advice. (1 hour 40 minutes)
 - a. Regional Public Member Updates:** Representatives from Cheshire and Merseyside, Greater Manchester, and Lancashire and South Cumbria each share updates. (5 minutes each)
 - b. North West SDE Public Member Updates:** Members share updates, including from the PPIE and Communications representative. (5 minutes)
 - c. Presentations from senior leaders in the SDE:** We listen to up to two presentations. Each presentation can last up to 20 minutes and will be followed by questions.
 - d. External Representatives:** We hear from external groups like the ‘National Institute for Health Research’. (15 minutes for 2-3 speakers)
 - e. Public engagement and Communications Coordinators updates:** Additional updates and information sharing. Including reviewing documents and reporting on progress being made. (5-10 minutes)
- 4. Requested Agenda Items:** Any specific items requested by members for discussion.
- 5. Any Other Business (AOB):** Any additional topics that need to be discussed.



How we will choose people

When someone agrees to join the group, we will send them a survey. This survey will ask about things like gender, ethnicity, disability, and other parts of their identity that are protected by law.

We want to have people from different backgrounds and experiences in the group. This helps make sure our discussions include everyone's views. Especially from communities that are often left out of important decisions. As some communities also have few people in leadership positions. Such as the NHS, Government and other large organisations. This can result in them being left out of designing services that are accessible to them too.

Because of this, we might choose people based on both their interest and their background.

If you're interested but not chosen right away, we will try to help you find other opportunities and keep you on a waiting list to join later.

